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REGULAR ARTICLE

On intimacy, sexual activities and exposure to sexual abuse among children and adolescents with mobility impairment

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Abstract

Aim: The aim was to describe experiences of intimacy and sexual activity and exposure to sexual abuse among children and adolescents with mobility impairment, and to relate these experiences to socio-demographic data, disability characteristics and well-being.

Methods: This study included semi-structured interviews with 141 children and adolescents aged 7–18 years with mobility impairment. Interpersonal experiences of intimacy and sexuality, socio-demographic data, disability characteristics and well-being were registered.

Results: About half of the children and adolescents in the study had been in a boy- or a girlfriend relationship, and about a fifth had an ongoing relationship. Of the adolescents, 15% had at least one experience of a sexual relationship. Whereas no particular sexual dysfunction was reported, 15% had concerns about their future sexual activities, presumably related to mobility impairment. A history of sexual abuse was reported by 7% in the age cohort of 13–18 years. The socio-demographic and disability-related features had a marginal influence on the experiences of intimacy and sexual activities.

Conclusion: Several aspects of sexual health are not fully realized for children and adolescents with impaired mobility, and there is a need for specialized sexual health care services to protect the sexual rights of this group.

INTRODUCTION

All of us are sexual, and sexuality is a part of children's and adolescents' development. As a contribution to the ongoing discussions on sexual health, The World Health Organization (WHO) presented a working definition of sexuality: 'Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors' (1).

Aspects of sexual development among children and adolescents with mobility impairment have already been described (2–5). However, there are few first-hand reports of experiences of intimacy and sexual activity. Stevens et al. (6) found that only one-third of adolescents aged 13–16 years with physical disabilities had ever been on a date. Cromer et al. (7) reported that adolescents with myelomeningocele had fewer experiences of having had sex compared to a control group. Suris et al. (8) found no differences in either sexual experience or the age of first intercourse between adolescents with visible and non-visible chronic conditions compared to matched control groups. Berman et al. (9) found that a majority (87%) of adolescents aged 12–22 years with congenital physical disabilities believed that they were able to have a sexual relationship, and 79% expected to have a sexual relationship in the future. However, none of the adolescents aged 16–18 years in the sample had ever had a sexual relationship. Potgieter and Khan (10) concluded that adolescents with spinal cord injuries experienced themselves as sexual beings with an interest in sex. The main barrier to expressing their sexuality was social attitudes, and a majority had concerns about their attractiveness as potential partners.

Childhood development and the transition to adult life are both influenced by individual as well as social and cultural contexts. Sexuality, in all its developmental stages, is intertwined with other basic developmental issues such as a formation of a positive self-concept and body image and a sense of trust for others (11). Mobility impairment involves unique issues for sexual development (4, 12). Restricted mobility and disability-related medical problems could interfere with and/or delay sexual development. Limited access to participation in social activities could influence the development of socialization skills, and thereby sexuality. Many children and adolescents with mobility impairment are dependent on their parents or other grown-ups to take part in peer interaction that might open up into intimate and sexual experiences (5). Stevens et al. (6) reported that adolescents with physical disabilities indicated that making friends and communicating with them was more problematic. Furthermore, young persons with disabilities are seldom described as sexual beings in the mass media, and several authors have pointed out that society by and large considers people with

disabilities to be asexual, unattractive, emotionally immature and incapable and uninterested in sexual activities (4, 5). Parents often avoid talking about sexuality with a child who has a physical disability because they do not believe that the child will ever have a sexual relationship (3, 13). Sobsey (14) have described the vulnerability of being subjected to sexual abuse among children and adolescents with disabilities. Moreover, Crosse et al. (15) reported an over-representation of maltreatment including sexual abuse among children with disabilities, and found 1.75 greater risk of sexual abuse in children with disabilities compared to children without disabilities.

The purpose of this study was to describe experiences of intimacy and sexual activity and exposure to sexual abuse among children and adolescents with mobility impairment, and to relate these experiences to socio-demographic data, disability characteristics and well-being.

METHOD

Participants

Participants and procedure have been described in detail previously (16). Children and adolescents were recruited from the two regional Child Development Centres (CDCs) in the municipality of Uppsala, Sweden, and three CDCs and all the schools with special classes for children with impaired mobility in the municipality of Stockholm, Sweden. Criteria for inclusion were mobility impairment and the ability to communicate in Swedish. Criteria for exclusion were mental retardation, deafness or severe hearing impairment, blindness or severe visual impairment and a neuro-psychiatric diagnosis.

This study included 141 children and adolescents (68 girls and 73 boys) aged 7–18 years (mean age 12.3 years) with mobility impairment. The sample was divided into the age cohorts 7–12 years (n = 72) and 13–18 years (n = 69), taken into consideration the expected age-related discrepancies between younger children and teenagers regarding intimate and sexual experiences. Socio-demographic data and disability characteristics of the participants in the two age cohorts are given in Tables S1 and S2 in Supplementary Material online.

Procedure

All children and adolescents were interviewed by the first author (LJ). Interpersonal experiences of intimacy and sexuality were addressed by a series of questions in a semi-structured interview that was based on the assumption that every individual is a sexual person. Further, the interview also addressed sexual problems and exposure to sexual abuse.

Measurements

This study includes results based on the variables of demographic data, friends and relationships, well-being, disability characteristics and sexuality (see Tables S1 and S2 in Supplementary Material online and Table 1). Perceived overall well-being was measured by the Snoopy scale, a nine-graded visual scale, with nine different facial expressions relating to different feelings or emotional states (16).

Table 1 Experiences of intimacy, sexual activities, sexual problems and exposure to sexual abuse among children and adolescents with mobility impairment by age cohorts

	Age cohort 7–12 y (n = 72) n/%	Age cohort 13–18 y (n = 69) n/%
Experience of playing doctor/family[a]	42/59	39/57
Experience of having a relationship	33/46	38/55
Present relationship	13/18	14/20
Desire to have a relationship[b]	18/32	28/51
Experience of,[c]		
Holding hands	17/52	29/91
Kissing	16/48	30/94
Hugging	16/48	31/97
Caressing	10/30	23/72
Sexual intercourse/caressing	–	7/22
Experience of sexual relationship[d]	–	10/15
Sexual problems[d]	–	10/15
Sexual abuse[d]	–	5/7

[a]Children 7–12 years (n = 71, 1 missing), adolescents 13–18 years (n = 68, 1 missing).
[b]Among children 7–12 years (n = 57, 2 missing) and adolescents 13–18 years (n = 55) with no present relationship.
[c]Among children 7–12 years (n = 33) and adolescents 13–18 years (n = 32, 6 missing) with experience of having a relationship.
[d]Adolescents 13–18 years (n = 68, 1 missing).

Intimacy and sexual activity

All children/adolescents were asked if they had played doctor/family, and if they ever had or wished to have a relationship (boyfriend/girlfriend). Those who at the time of the interview had an ongoing or former relationship/s were asked about experiences of holding hands, kissing, hugging and caressing. Questions about any experience of a sexual relationship (on one or several occasions) were asked to adolescents aged 13 years and older. Out of those, for adolescents who at the time of the interview had a boyfriend/girlfriend, experiences of sexual caressing and intercourse were also recorded (yes or no).

Sexual problems

Respondents aged 13 years and older were asked if they had any difficulties regarding their sexuality (yes or no). Possible problems exemplified by the interviewer were erectile dysfunction, premature/retarded ejaculation, anorgasmia and decreased desire. Answers in the affirmative were followed by the questions: 'Do you have somebody to turn to with your problem?' and if not: 'Do you wish that you had somebody to turn to?' and if they did: 'Do you want me to help you with that?'

Sexual abuse

Sexual abuse is defined as: 'any sexual contact between an adult and a sexually immature child (sexual maturity is socially as well as physiologically defined) for purposes of the

adult's sexual gratification; or any sexual contact to a child made by the use of force, threat, or deceit to secure the child's participation; or sexual contact to which a child is incapable of consenting by virtue of age or power differentials and the nature of the relationship with the adult' (17). Exposure to sexual abuse among the adolescents aged 13–18 years in the study was addressed with two questions: 'People can sometimes get involved in sexual activities without actually wanting it themselves. Have you at any time been involuntarily involved in any sexual act?' and 'People are sometimes forced into sexual acts. Have you at any time ever been forced into any sexual acts?' (yes or no). As a matter of routine, those who answered affirmatively were asked if they had received any help, and if they wanted the interviewer to assist them in any way regarding possible problems associated with sexual abuse. The entire purpose of the follow-up questions was to offer support to the respondent, and responses to these questions are therefore not accounted for in this study.

Statistical methods

All statistical analyses were carried out using LogXact® 7. Results were considered statistically significant if the p-value was less than 0.05.

We used exact logistic regression to analyze the univariate relationships between the intimate and sexual experience variables (8 for children aged 7–12 years and 12 for adolescents aged 13–18 years), and the different explanatory variables (7 on demographics, 12 on disability characteristics and 5 on social relationships, future aspirations and well-being). To determine which of the explanatory variables were the most important in predicting the experience variables, we used exact multiple logistic regression. The starting models were based on the significant variables in the univariate analyses (Tables S3 and S4 in Supplementary Material online) included and excluded in a stepwise procedure. The results from the fitted regression models are presented as odds ratios (OR) together with corresponding 95% confidence intervals (CI).

Ethics

The study was approved in 1998 by the Research Ethics Committee at the Faculty of Medicine at Uppsala University (registration number 98384).

RESULTS

Age cohort 7–12 years

Experiences of intimacy

Almost half of the children (n = 33, 46%) reported that they had been in a boyfriend/girlfriend relationship, while 18 responded that they would like to have such a relationship (Table 1). All relationships were with the opposite sex. Experience of different intimate acts such as holding hands, kissing, hugging and caressing among these children (n = 33) ranged from a low of 30% (caressing) to a high of 52% (holding hands). Thirteen children (18%) reported that they had an ongoing relationship at the time of the interview.

Experiences of intimacy in relation to socio-demographic data, disability characteristics and well-being

In the final multiple logistic regression models, the experience of playing doctor/family was significantly associated with gender. Thus, girls had played doctor/family to a greater extent than the boys (OR 12.5, CI 3.10–74.5). Furthermore, children with severe speech impairment had significantly less experience of playing doctor/family (OR 8.61, CI 1.27–86.3). Children with urinary incontinence and pain had significantly greater experience of having been in a relationship (OR 4.01, CI 1.06–17.9 and OR 3.24, CI 1.07–10.6, respectively). Further, those who suffered from faecal incontinence were nearly five times as likely to be in a present relationship (OR 4.63, CI 1.03–20.9). However, we found no significant differences between a wish to have a relationship or inter-relational intimate experiences, and the independent variables.

Age cohort 13–18 years

Experiences of intimacy and sexual activity

In the older age group, more than half of the boys and girls (n = 38, 55%) had experiences from a heterosexual relationship, and 28 reported that they would like to have such a relationship (Table 1). Among these adolescents (n = 38), a majority had taken part in different intimate acts (holding hands, kissing, hugging), while 23 reported experiences of caressing. Fewer (n = 7) reported sexual caressing and sexual intercourse (n = 6). Furthermore, a minority of the adolescents reported that they had been in a sexual relationship (n = 10, 15%). Fourteen adolescents (20%) reported that they had a current relationship at the time of the interview.

Experiences of sexual problems

Fifteen percent of the adolescents aged 13–18 years reported concerns about sexual activities (n = 10). Most of them (n = 7) had experienced a relationship. However, only three had been in a sexual relationship. Six adolescents stated their sexual worry/worries, and all were concerned with future sexual experiences. No sexual dysfunctions were reported. Examples of disability-related sexual worries were: their personal assistant would get too much insight in their sexual activities, questions on reproduction ('Could I have a child?'), being questioned as a parent, realization of sexual intercourse ('How is it done?') and concerns regarding a future partner ('Will I get an understanding girlfriend?'). Examples of general sexual worries were concerns about physical appearance and pain in connection with sexual intercourse. More than half of them had no one or nowhere to turn to with their problems (n = 6). Five of these six adolescents expressed a wish to discuss their concerns about sexuality with a skilled professional, and answered in the affirmative to the follow-up question as to whether they would like the interviewer to help them get in contact with a sexologist.

Exposure to sexual abuse

Among the adolescents aged 13–18 years, one boy aged 14 years and four girls aged 14–16 years (7%) reported

exposure to sexual abuse. We found no differences in exposure to sexual abuse with regard to socio-demographic or disability characteristics.

Experiences of intimacy and sexual activity in relation to socio-demographic data, disability characteristics and well-being

In the final multiple logistic regression models, having a current relationship was significantly more common among those with urinary incontinence (OR 8.73, CI 2.01–41.9). Further, expressing a wish to have a relationship was significantly more frequent among those with scoliosis/kyphosis (OR 5.63, CI 1.15–38.7) and those with a lower level of perceived overall well-being (OR 1.33, CI 1.005–1.85). The experience of holding hands was significantly greater among those with higher motor capacity (OR 1.03, CI 1.003–1.08). In the analysis of caressing, all of the included significant variables from the simple logistic regression analyses, except for future aspirations, were weighted out. Thus, adolescents who expressed their future aspirations of living together with a partner and eventually having children were 26 times more likely to have experiences of caressing (OR 25.9, CI 2.04–1570) than those with future aspirations of living together with a partner, but without children. Experiences of sexual intercourse/caressing increased significantly with a higher age (OR 1.88, CI 1.06–3.81). However, we found no significant relationships between experiences of playing doctor/family, having been in a relationship, having had a sexual relationship, kissing, hugging, sexual problems, exposure to sexual abuse and any of the independent variables.

DISCUSSION

The main finding of this study is the marginal influence of both socio-demographic and disability-related features on intimacy and sexuality for children and adolescents with mobility impairment. A majority expressed their future aspirations of living together with a partner and having children. Although many had limited or no experience of inter-relational intimacy and sexual activities, they clearly identified themselves as sexual beings. A greater experience of intimacy was associated with an estimation of oneself as a future partner and parent.

Initially we will state some possible methodological limitations within this study. Notably, all variables in this study were reported at the same point in time. Hence, we do not discuss causalities but instead co-occurrences and likelihoods. Among the significant associations in simple and multiple regressions, quite a few rather high odds ratios were indeed found. Yet the confidence interval in some observations was so close to one that at least the clinical meaningfulness could be questioned. Further, the remarkable widths of several 95% confidence intervals indicate the limitations of the relatively few observations and individuals as outliers. Another possible limitation is that the children and adolescents themselves idiosyncratically defined a particular variable. For instance, the reported experiences from 'ever had a relationship' and 'holding hands' can, especially for the younger children, have vastly different meanings. One example of the affirmative reporting of having a relationship for a boy aged 7 was 'being together on Thursday'. Hence, the perception of having a relationship could effect the associations to the socio-demographic and disability-related explanatory variables. Even though we acknowledge these limitations, we have chosen to perform multiple exact logistic regression analyses based on the results of simple logistic regression analyses, as an attempt to explore these complex associations.

Age cohort 7–12 years

Fortunately, children aged 7–12 years with mobility impairment in the study did report experiences of having had a relationship, as well as experiences of holding hands, kissing, hugging and caressing. Still, more than half of them had no experiences of different intimate acts, and many expressed a wish to have a relationship. Experiences of intimacy among younger children with impaired mobility are largely unexplored, since most studies concern adolescents aged 13 years or older. However, a Swedish study (18) actually including children from the age of 7 years demonstrated that children with restricted mobility had considerably fewer peers in their social network compared to children without disabilities. The authors suggest that these differences depend on both physical and social barriers. The relatively few children in this study with intimate experiences could be explained by a smaller social network and, consequently, limited opportunities to explore close relationships with others (19,20).

Perhaps the finding that girls in the study had more experience of playing doctor/family than boys reflects a gender difference in development. Severe speech impairment creates apparent difficulties in playing doctor/family, and children with this additional disability appeared to generally need special help from adults to benefit from role-playing together with peers.

In contrast to the common understanding of incontinence as an obstacle for intimate relationships, children in our study with urinary and faecal incontinence reported more experiences of having had or being in a present relationship. Similarly, those with the presence of pain had more experiences of having had a boyfriend/girlfriend. Evidently, these significant associations with confidence intervals close to one indicate a limited effect. Tentatively, incontinence *per se* does not interfere with making contact with others in this age group. The presence of pain could inversely encourage contact-seeking to receive alleviation of one's pain, which possibly promotes close relationships to others. Furthermore, in Sweden children with urinary incontinence, who use intermittent and indwelling catheterisation, are offered specialised care by registered nurses with education in uro-therapy, which provides the opportunity for extended information and support on sexual matters.

Age cohort 13–18 years

Half of the adolescents aged 13–18 years had experience of a relationship. However, many of the adolescents expressed a wish to have a relationship, a result that reflects an adequate psycho-sexual development.

A population-based study of sexual attitudes and behaviour in Sweden (21) demonstrated that at the age of 19 years a vast majority had experienced sexual intercourse (92% women and 87% men). Another Swedish study (22) of sexual experiences and behaviour among 17-year olds without disabilities demonstrated that more than half of the boys and 64% of the girls had experienced sexual intercourse. In this study, as few as seven of the adolescents had experiences of sexual caressing and intercourse within a partner relationship, and 10 out of 68 reported experience of at least one sexual relationship. This result clearly indicates limitations for young people with mobility impairment to take part in sexual activities. This has also been demonstrated in other studies (23–25).

This restricted sexual experience is further illustrated by the adolescents' own concerns and worries regarding their future sexuality. A majority of these worries are disability related. These findings are in accordance with others who have described insignificant experiences of intimate relationships (26) and major concerns about relationship matters among teenagers with disabilities (10, 26). None of the adolescents in this study had received any kind of support or help to approach their problems, and most were in need of professional care. What is noteworthy is that none reported any particular sexual dysfunction. This is probably best explained by a lack of partner-related sexual experience and also by the very young age of the sample.

Several authors have reported that young people with spina bifida have serious concerns about urinary incontinence and sexuality (27, 28). In this study, adolescents with urinary incontinence were more likely to have a present relationship than those without incontinence. This finding corresponds well with Castree and Walker (27), who found no evidence that those with a urinary appliance were any more isolated than those without one.

We have no explanation for the finding that adolescents with scoliosis/kyphosis were more likely to express a wish for a relationship. Having a close relationship is important for well-being, which could explain the finding that those adolescents who estimated a lower level of well-being were more likely to express a wish for a relationship. Further, the fact that adolescents with a higher motor capacity were more likely to have experienced holding hands could partly be explained by these adolescents having an improved motion ability.

An even more complicated issue concerning sexuality among young people with mobility impairment is that of sexual abuse. Earlier studies support the finding that children with disabilities are at a higher risk of exposure to sexual abuse than children without disabilities (15, 29). Quite similar figures for the exposure of sexual abuse among young people with disabilities, 10% and 7%, were reported by Blackburn et al. (30) and by us in this study. In a previous study of sexual abuse among Swedish women aged 18–74 years, 12% had a history of any kind of sexual abuse (31) and in the same sample, 3% of the men reported sexual abuse (21). Even though there is a general risk of sexual abuse in children and adolescents, it is important to recognize the extra vulnerability associated with having impaired mobility (32).

Even though specific issues for sexual development among young people with disabilities have been recognized for quite some time (12), the attitudes among parents as well as professionals indicate that they are uninformed regarding these matters. Remarkably, prior to the interview none of the teenagers had expressly been asked questions on sexuality, and several of them spontaneously reported on being excluded from sex education in school. For instance, one girl reported that before a theme day devoted to sex education in her school, her teacher suggested that she should book time at her physiotherapist or orthopaedic clinic to make use of the time, since the theme day did not concern her.

As presented by the WHO (1), good sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled. Sexual rights include the highest attainable standard of sexual health, including access to sexual and reproductive health care services.

We conclude that several aspects of sexual health are not fulfilled for children and adolescents with impaired mobility, and that there is a need for specialized sexual health care services to protect the sexual rights of this group.

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Supplementary material

The following supplementary material is available for this article:

Table S1 Socio-demographic data among children and adolescents with mobility impairment

Table S2 Disability characteristics among children and adolescents with mobility impairment

Table S3 Simple logistic regressions, odds ratios and 95% confidence intervals for the significant associations ($p < 0.05$) between the experiences of intimacy and the independent variables among children with mobility impairment aged 7–12 years ($n = 72$)

Table S4 Simple logistic regressions, odds ratios and 95% confidence intervals for the significant associations ($p < 0.05$) between the experiences of intimacy and sexual activities and the independent variables among adolescents with mobility impairment aged 13–18 years ($n = 69$)

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